



**Governor's Advisory Council
To The Division of Developmental Disabilities**

April 18, 2018

1056 Governor's Avenue
Dover, DE

Council Members:

Terri Hancharick, Chair
Tim Brooks
Stan Trier
Susan Pereira
Angela Sipple
Tom Rust

Staff Members:

Marie Nonnenmacher, Director
Marissa Catalon
Katie Howe
Terry Macy
Lynda Lord
Jim Dickinson
Rick Kosmalski
Nicole Lawless, Minutes

Guests Present:

Terry Olson, The Arc of Delaware
Vivian Turner, CERTS, Inc.
Cory Nourie, Nemours

Review of Previous Meeting Minutes

Council members reviewed and approved the minutes from the March 2018 meeting.

Old & New Business

Census

The GAC agreed to defer the census until the May 2018 meeting.

A.I. DuPont Transition Program Presentation

Cory Nourie led a presentation on the Nemours transition program.

Nemours currently has an age limit of 21 with minimal exceptions such as hospitalization on a 21st birthday and complications from a previous surgery at Nemours. Nemours also has two categorical exceptions: skeletal degeneration and heart conditions. Patients with skeletal degenerations may remain at Nemours until their 35th birthday. Patients with heart conditions may remain until their 40th birthday.

The transition program currently consists of 90-minute sessions with families focusing on the medical aspects of transition. This includes updating medications, completing medical records, reviewing available support services through DDDS and other organizations, and providing families with a complete plan prior to transition. The program works hard to prepare families for the difference in adult care and reviews options with families based on their insurance and support needs.

Transition planning typically begins around 18 ½ years of age with support from a two-person team. The average length of counseling is 13 months with a goal of meeting at ages 16 and 18, then yearly from that point on to help connect the patient with adult doctors. Planning sessions also include conversations about sex with parents and clients, detailing how to protect themselves, contraceptive options, and potential vulnerability. The program has worked with over 1,000 individuals to date and currently serves about 50% of the State of Delaware.

During the presentation, Cory discussed weaker areas in adult care such as neurology, urology, and dental care (a weak area in both adult and pediatric care). Gaps during transition in these areas can create difficulties for families. Other unmet needs include ongoing residential supports for families, information about legal status at age 18 and guardianship discussions in school, estate and trust planning, and psychiatric care.

Reportable Incidents Summary Analysis FY15-FY17

Jim reviewed the Reportable Incidents Summary Analysis for FY15-FY17 with GAC members. The document provides a high-level look at DDDS data as a snap shot of the last three years. This document was previously sent out to providers and contractors as a resource.

GAC members agreed DDDS did a good job of explaining ongoing issues within the report and suggested the Division make the report available on the DDDS website with a more detailed definition of neglect in the future. A new data system will allow DDDS to subcategorize instances of neglect in the future (medication error, understaffing, etc.).

Members also expressed an interest in seeing a data report that covers falls. All falls are a reportable incident and are to be reported to DDDS. When received the Division checks to see if protocol was followed. If not, and investigated is conducted.

It is the goal of the Division to have a larger amount of granular data available in the future to help manage the organization. In continuation from previous leadership, DDDS is actively moving from being a service organization to an oversight organization.

Waiver & LTSS Comparison Handout for Families

Both comparison handouts are currently under review by DMMA. DDDS expects to receive a response soon.

Other Business/Announcements

GAC members asked Rick to share his plans for family engagement and self-advocacy. Rick explained that communication is a major component of the plans. The goal is to break down barriers and set expectations through communication. DDDS is looking to improve cultural confidence in the division, help nurture a strong self-advocacy group, and help increase parental advocacy. Rick shared with members that he has met with DDDS leadership to determine family engagement needs and plans to share more information once structured plans have been prepared. Rick welcomed feedback from the GAC as members expressed the need to increase outreach and provide information to families who do not know that DDDS services exist. Members also suggested that Rick attend the Self-Advocates Becoming Empowered (SABE) conference.

Community Services has actively engaged with the Center for Special Health Care Needs. The center conducted a dental presentation for Support Coordinators and will return in a few days to lead a presentation for Community Navigators.

Jim announced the stakeholder meetings recently had their first individual participant. The group is looking forward to increased participation.

Future Meetings

FY 2018 Governor's Advisory Council meetings will occur the third Thursday of the month at 11:00 a.m.

June 21, 2018	11:00 a.m. – 1:00 p.m.
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